ALERT

THE UNIVERSAL FELLOWSHIP OF METROPOLITAN COMMUNITY CHURCHES

News from the UFMCC on AIDS Legislation, Education, Research and Treatment.

NOVEMBER, 1987

MORE GOOD NEWS

In a paper from the University of California, San Francisco, School of Medicine, George F. Solomon, M.D., Lydia Temoshok, Ph.D., Ann O'Leary, Ph.D., and Jane Zich, Ph.D. describe "An Intensive Psychoimmunologic Study of Long-Surviving Persons With AIDS." The purpose of the study is to understand how long-term survivors are different from people who follow the expected course of the disease.

"While the prevalent belief...is that AIDS is invariably fatal, there is a growing number of individuals who are alive and well three, four, and even five years after an AIDS diagnosis." Citing California Department of Health Services analysts, they state that 50% of AIDS patients will survive a year, 30% two years, and 2% will survive five years. If there are currently 41,000 diagnosed cases, then 820 of those people will still be alive in five years.

A number of common factors thought to be significant to long-term survival were described:

(1) Long term survivors understand and accept the reality of the AIDS diagnosis, but also refuse to believe that the syndrome is an automatic, imminent death sentence.
(2) They believe that one can cope actively with the disease, and refuse to succumb to a "helpless-hopeless" state.
(3) They make appropriate, individualized adjustments in personal habits and behaviors to accomodate living with the disease.
(4) They see the physician as a collaborator, and do not fall into a passive or compliant mode when interacting with the physician; they take an active part in decisions related to treatment.
(5) They display a belief that the individual patient can influence the outcome of the disease: a sense of personal responsibility for health.
(6) There is a perceived "commitment to life" to take care of unfinished business; a sense of unfulfilled goals or dreams.
(7) Survivors find meaning and purpose in life.
(8) They identify a sense of meaning in the disease itself.
(9) There is usually a previous experience with beating a life threatening illness, or overcoming difficult situations and events.
(10) A program of exercise and physical fitness is a common factor.
(11) Long-term survivors report the importance of support and information from other people with AIDS, particularly shortly after diagnosis: no one understands quite like another person with AIDS.
(12) Commitment to helping other persons with AIDS seems to have a sustaining quality in and of itself.
(13) Long term survivors seem to share a basic level of assertiveness and the ability to say "no."
(14) Long term survivors give themselves permission to withdraw from involvements when they need to care for themselves.
(15) There is a developed ability to "read" one's body, and to sensitively care for it.
(16) There seems to be a common ability to communicate openly, including concerns about health issues.

Interestingly, the authors suggest that gay men who have learned to be comfortable and open about being gay tend to adopt more smoothly to living with their diagnosis of AIDS than those for whom coming out is still an issue.

The authors stress that this is a preliminary report, and should be "interpreted with caution." As the study continues, it is hoped that more will be learned about why some people live longer with AIDS. That will eventually enable more people to live with AIDS longer than the usual prognosis of 18 months to two years.

CONTACTS FOR THE BATTLE

Rev. Elder Freda Smith has supplied ALERT with the following important information:

AIDS LEGAL RIGHTS HANDBOOK

NGRA
540 Castro Street
San Francisco, CA 94114
(Free with self-addressed stamped envelope)

PWA COALITION NEWSLINE

263A West 19th St. #125
New York, NY 10011
(Monthly articles and information for and by persons with AIDS and ARC. Free to all PWA's and PWArc's, all others $20.00)

AIDS: A POSITIVE APPROACH by Louise Hay

Hay House
3029 Wilshire Blvd., #206
Santa Monica, CA 90404
(A self-healing audio tape)

INFO ON CURRENT DRUGS

AZT Federal Hotline	800-843-9388
DNCB Information	415-647-8561
Bay Area Ribavirin Interest Group	415-845-2205
Project Inform	800-822-7422

AL 721: For a packet of five articles, including the recipe for homemade AL 721 "workalikes", send one dollar to John S. James, P.O. Box 411256, San Francisco, CA 94141. James is the publisher of AIDS Treatment News.

MINORITIES CONFERENCE AT THE CDC

At an August conference on AIDS and Minorities, held by the Center for Disease Control in Atlanta, Blacks, Hispanics, Asians, and Native Americans demanded more input and influence in AIDS education, as well as more direct funding for Minority AIDS agencies and programs.

Brandy Moore, a spokesperson for the Black caucus, criticized the federal government for appropriating funds for Minority education "without significant input from the Black community." This results in excluding minorities "from the resources -- and the power -- to control our live."

The director of the CDC, Dr. James O. Mason, reported that Congress had directed the $7 million to be awarded to state agencies rather than directly to minority-based groups. However, he said the CDC would extend the deadline for grant applications, if possible, to give Minority agencies a greater chance to apply for funds from the $7 million.

Black and Hispanic activists demanded increased minority input and presence on CDC planning and review panels. Ruth Rodriguez, in demanding a Latino advisory board (to include Hispanic persons with AIDS) pointed to the "disregard and insensitivity demonstrated by CDC for those latinos struggling against AIDS."

Although Blacks and Hispanics comprise 19% of the U.S. population, they comprise 38% of all AIDS cases, while among children with AIDS, 80% are Black and Hispanic.

In an article in the Chicago Sun Times on August 10, 1987, Mason said, in response to the idea of Minority advisory panels, "I think it's a good idea. We'll look at that and see where we can increase minority input."

AND IN OTHER NEWS...

ENDING A LONG-STANDING FEUD BETWEEN FRENCH AND U.S. SCIENTISTS, Dr. Robert Gallo of the U.S. National Cancer Institute, and Dr. Luc Montagnier of the Paris Pasteur Institute, who are acknowledged as the Co-Discoverers of the HIV virus, agreed to commit themselves to collaborate, sharing data and materials via satellite hookups. This will be part of the World Immunological Network, and will use the Hospital Satellite Network.

THE WORLD HEALTH ORGANIZATION REPORTS that as of Sept. 23, 1987, 151 countries have reported 60,552 diagnosed cases of AIDS. This is compared to 111 nations reporting 52,565 cases on June 15. Many individual countries' statistics are as old as mid-1986. The United States has reported the largest number of AIDS cases, with 41,735. The next largest concentration is in France, with 1,980 reported cases. However, the Pan American Health Organization estimates that in Latin America, the actual number of AIDS cases may be two to four times greater than reported. The same may be assumed about some other underdeveloped nations, with less sophisticated reporting capabilities.

ITZHAK BROOK, M.D., writing in the Sept. 18 Journal of the American Medical Association, warns physicians against misusing AZT for HIV patients who are asymptomatic, or exhibit mild symptoms. Brook, who chaired the committee that recommended AZT for early FDA approval, feels that for patients who are very sick, the drug's benefits outweigh the potentially toxic side effects; however, he warns that the benefits for patients in earlier stages of HIV infection have yet to be fully proven, and use of the drug in these patients needs to be carefully monitored.

NIAID DIRECTOR DR. ANTHONY FAUCI CALLED AIDS TREATMENT EVALUATION UNITS' progress "remarkable", in response to criticisms heard during an Institute of Medicine meeting which focussed on AIDS drug development. Fauci defended the expanding programs to test AZT in patients with ARC, Kaposi Sarcoma, AIDS-related dementia, and in asymptomatic carriers and also reported that AL 721 has been approved for Phase 1 trials at ATEU's, and that the ATEU network is actively investigating 23 AIDS drug trial protocols, while two more protocols have just been approved by the FDA.

THE NATIONAL FUNERAL DIRECTORS ASSOCIATION has advised all funeral directors to assume that every body they work on is infected with HIV. Appropriate precautions are advised, to prevent infection from body fluids.

A DENTAL CLINIC FOR PEOPLE WITH AIDS has been opened by the Bering United Methodist Church in Houston, Texas. More than 100 people are on the dental clinic waiting list. Clinic materials and facility improvements have been funded by other religious organizations in Houston.

THREE MONTHS AFTER PRESIDENT REAGAN'S CALL FOR HIV SAMPLE TESTING, public health officials have still been unable to begin the program. Originally, 45,000 people were to be tested and results disclosed within six months of Reagan's May 31 request. However, no strategy or timetable has yet been established. Government experts report "cautious optimism" that the program will begin soon.

CHURCH PROGRAM FOR AIDS MINISTRY

In future issues of ALERT we would like to share what our churches are doing for AIDS Ministry programming. If your church has a current program that you would like to share with the Fellowship, send it to:

REV. STEVE PIETERS
UFMCC: ALERT
5300 Santa Monica Blvd., Ste. 304
Los Angeles, CA 90029

Please make sure your descriptions do not exceed 350 words and are presented in a legible manner.

FEEDBACK

We want ALERT to provide you with helpful information in a timely way. If you have suggestions or comments on how ALERT can be more useful to you, please write to Rev. Steve Pieters at the address above.

UFMCC VIGIL OF PRAYER
NOVEMBER 7-8, 1987

DNCB AIDS/ARC TREATMENT

by John S. James

There's more to DNCB than meets the eye. This writer had ignored the story, because it appeared confusing and not very important. But patients using DNCB persuaded me to take a closer look - and a very different picture emerged.

Researchers have not completed rigorous clinical studies of DNCB, so we don't have definitive scientific proof of its effectiveness. But the evidence we do have clearly places DNCB among the most hopeful treatment possibilities currently available. And the ongoing work with DNCB is providing new insights into AIDS, and into the differing treatment needs of different classes of patients.

DNCB is other stories, too. The lack of institutional DNCB research has led to a network of "guerrilla clinics", now in 14 U.S. cities and growing almost daily. These groups are supplying each other with batches of DNCB lotion and instructions for use, on the condition that the lotion never be sold but always given away free.

The dangers may be small, but doctors are concerned at the lack of scientific testing and of medical supervision. And yet, for most people, the guerrilla clinics will remain the only alternative - until institutional science and medicine gives this treatment the attention it deserves. (At this time we know of physicians using DNCB in only five cities: San Francisco, Berkeley, Los Angeles, San Diego and New York.)

A Brief History

DNCB (dinitrochlorobenzene) is a chemical that affects the body much like poison oak. It penetrates the skin and binds onto protein there, rendering these proteins much more likely to stimulate an immune reaction. In a person who has normal immunity, DNCB causes a rash like poison oak. The pure chemical is so strong that it must be diluted almost a thousand times before use.

Immunologists have used DNCB extensively in their research. Several years ago, Dr. Bruce Mills - then a Stanford research dermatologist studying the biochemistry of certain enzymes - observed that DNCB successfully treated a kind of severe warts, in children, that could not be effectively treated conventionally. Not only did the treated wart disappear, but all the other warts on the body, too. It turned out that the DNCB stimulated the development of T cells, correcting the immune defect which had allowed the warts to develop. The DNCB treatment - for certain kinds of warts - has become generally recognized as effective.

Next, Dr. Mills, now a physician in private practice in San Francisco, tried DNCB for treatment of KS lesions in persons with AIDS. Not surprisingly, it turned out that KS was more difficult to treat than the warts. But there were dramatic improvements in many cases, and not only for KS. Recently, Dr. Mills has distinguished four groups of AIDS/ARC patients. Different treatments are appropriate to the different groups.

The Four Groups of Patients

Dr. Mills' patients not only receive DNCB; they also receive extensive monthly laboratory blood tests, whenever financially possible. The resulting data has led Dr. Mills to the following classification of patients:

The first question asked when he groups AIDS/ARC patients is whether the level of gamma globulin (immune globulins) is extremely high, close to 3000 or worse. If so, there is a problem from too much antibodies. Dr. Mills calls these patients Group III (discussed below).

GROUP I:

These patients get the most dramatic benefit from DNCB. Their immune globulin level is not too high, and these patients respond well to DNCB in three to six months - in laboratory tests and by clinical improvement. These patients may not need any other treatment than DNCB.

Note that it does take time to get results, however. That is because DNCB works by stimulating the growth of new T cells, and it takes time for these cells to be produced and to mature.

GROUP II:

These patients also have a reasonable immune globulin level, but they do not respond well to DNCB in three to six months. Dr. Mills believes these patients may also need an antiviral.

GROUP III:

These patients, mentioned above, have the problem of too much antibodies. For these patients, many of the other lab results are unreliable. Dr. Mills hopes that about a year of treatment with DNCB can reduce the immune globulin level.

GROUP IV:

This is end-stage AIDS. DNCB may raise the T cell counts a little, but it is too late to save the person's life. Note that Mills' classification is different from the normal distinction of ARC vs. AIDS, and that many patients with pneumocystis or KS (for whom most doctors have all but given up) would not be in group IV, but in one of the other three groups.

How is DNCB Used?

Usually, a small amount of DNCB (2/15 of one percent) is dissolved in Vaseline Intensive-Care lotion. Sometimes other solutions are used. Once a week, the doctor paints a small patch on the arm, covers it with gauze, and tells the patient to remove the gauze and wash off the DNCB lotion in a certain number of hours. The DNCB should cause a rash to appear on the skin. Patients with a suppressed immune system will not react at first, but everyone tested so far has eventually achieved a reaction.

Sometimes the DNCB is painted directly on KS lesions, but usually only after a skin reaction has already been achieved elsewhere.

Dr. Mills also has patients take about a dozen blood tests. These include T cell subsets, immune globulins, lymphocytes, and platelets. Also included are blood lipids,

liver function, and other tests to warn of any dangerous side effects of the DNCB; so far, none has been found. In addition, he runs standard tests for rheumatoid arthritis, lupus, and syphilis, even though the patients do not have these conditions, because positive results may indicate a malfunctioning immune system.

A Case History

We spoke with one patient - not referred to us by Dr. Mills - who is considered a star patient, because there are no complicating factors in his case. He started treatment early while severly immune suppressed but not otherwise ill. He took no other treatments and had no opportunistic infections or other illnesses during the treatment. He received extensive lab work on several occasions, so there is much data available to study. And he continued the DNBC treatments without interruption in the ten months he has been Dr. Mills' patient. When he began treatment, his helper/suppressor ratio was .22, and absolute helpers 118. At that time he read an article that claimed that it was impossible to reconstitute the immune system if the helper number was less than about 245.

For the first five months, the number went up, but just a little: 118, 265, 295, 365. At that time he was discouraged and had no further tests done for four months, but he continued the DNCB. When retested, in June 1986, the helpers were 529, (within the normal range of 447-1284). In Sept. they rose to 707. Total T cells went from 686 at the beginning, to 2259. The helper/suppressor ratio had climbed from .22 to .63 - not yet normal, but a major improvement.

Meanwhile, all the other lab tests moved in the right direction (or stayed normal). Immune globulins decreased from 2600 to 1830 (normal range is 540-1480). Lymphocytes increased from 1400 to 2700 (normal is 800-3200). Hemoglobin improved from 12.7 to 15.3 (normal is 13.9-18). The lupus and rheumatoid arthritis tests went from positive to normal; the "syphilis" antibodies dropped.

The patient told us that Dr. Mills believes that it may eventually be possible to stop using the DNCB, but he isn't sure yet.

Despite these results, the patient is unsure how many others will have the persistence to follow the treatment consistently, even though the results are slight for the first several months. When he started DNCB, he was feeling well; he had only a positive antibody test. Fortunately, he than took the T cell subset lab test, which showed that though he was feeling well, he was living on borrowed time; it is surprising that he had not already developed pneumocystis or other problems. He began the DNCB treatment immediately and stayed with it.

Since this patient was well throughout, there was no opportunity to observe clinical improvement. Many others have shown major clinical improvement, including a resolution of nailbed fungal infections, KS lesions (even severe ones) that have almost disappeared, and generally feeling better and having more energy.

What's Needed Now?

The above case history, and the 26 others summarized by Dr. Mills in his letter published in the June 1986 Journal of the American Academy of Dermatology, are not scientifically conclusive. The reason is that patients in a private practice are self selecting. Those who don't think the treatment is working usually leave, so that only the good results tend to be reported. We need well-designed, controlled clinical studies to prove the effectiveness of DNCB, and to provide further information on exactly how to use it most effectively.

We have heard reports that such studies are now beginning in New York and Los Angeles, but have not been able to investigate these reports by press time.

In San Francisco, Dr. William L. Epstein, Chairman Emeritus of the Department of Dermatology at U.C. Medical Center, wants to perform a study of DNCB (and also urushiol, the active ingredient of poison oak) for AIDS as well as other immune diseases. Dr. Epstein is President of the American Academy of Dermatology and the world's foremost expert on contact skin sensitization (such as caused by poison oak or DNCB). But, so far, the study has not been approved. The rumor we have heard - not from Dr. Mills, nor from Dr. Epstein, who was not contacted for this story - is that the study was first denied funding, and then also denied permission to use patients; and that the reason the study was prohibited was rooted in the politics of personal and professional rivalries, including the fact that cancer specialists - not immunologists - have held political control of AIDS research.

Any physicians interested in studying or using DNCB for AIDS or ARC should note that, as far as we know, there have never been harmful effects from such use, except that with occasional patients the expected skin reaction can be severe. Dr. Mills does not know of any kind of AIDS/ARC patients who should NOT get DNCB, although clearly it will help some groups of patients more than others. DNCB is already used in medical practice, and a pharmacy can mix it for use. The cost is negligible. Application requires only a Q-tip, once a week, plus ordering standard laboratory tests. In short, there are no technical obstacles to wider use of DNCB, nor to conducting the kinds of studies needed to get definitive answers on its value for AIDS or ARC.

For More Information

For information about DNCB and the guerrilla clinics, call Jim Henry, at (415) 647-8561. He can tell you whom to contact near your area about using DNCB.

Another information source is the Project Inform Hotline (800-334-7422 within California; 800-822-7422 from other states). Project Inform is primarily interested in ribavirin, but is also aware of DNCB, as the two treatments might complement each other.

AMPLIGEN: EXPERIMENTAL DRUG WITH PROMISE

by: Dr. Gary McClelland

As with all catastrophic illness, a variety of treatment regimens has sprung up around AIDS - some beneficial, some toxic, some ineffective, and some downright fraudulent. This very diversity points to the fact that there will probably be no one treatment or "silver bullet", but that in the end a combination of treatment modalities will be used.

The two goals of treatment in AIDS are to inhibit or prevent replication of the virus and to repair the damaged immune system, and to do this with a minimum of adverse side effects. Before a drug can be released for use by physicians it must undergo extensive testing, both laboratory and human studies, to determine its safety and effiency - its risk-benefit ratio. Some drugs such as Suramin have been abandoned because of severe toxic side effects. This process, which is monitored by the FDA, seems tediously slow to most of us who are daily faced with the frustration of this life-threatening illness for which there is no effective treatment to date. It is for this reason that a network of guerilla clinics offering alternative treatments, unproven by authorities but not necessarily ineffective, have sprung up throughout the country. Future editions of this column will focus on some of these alternative treatments.

All of us were heartened by the early release of azidothymidine (AZT), an antiviral drug, by the FDA in Sept. 1986 and certainly it has had beneficial effects on prolonging both the length and quality of life of PWA's. Unfortunately, one of its serious side-effects has been bone marrow suppression causing severe anemia and transfusion dependency in up to fifty percent (50%) of those on the drug. This has required stopping the drug or decreasing its dosage. Recent studies have also shown that many patients on AZT for longer than eighteen months are losing the weight they had regained initially and are developing a recurrance of life-threatening infections. This has occurred primarily in the patients with advanced disease and not in ARC patients. It may well turn out that the best use of AZT is in those who are HIV positive but asymptomatic or in ARC patients. Or it may be that AZT can be used at a lower, less toxic dose in combination with a drug that potentiates its effect.

Such a drug is the experimental drug Ampligen, a mismatched double stranded RNA, which is currently being tested on AIDS and ARC patients in a collaborative study at five US medical centers. Ampligen appears to manifest its beneficial effects by inhibiting replication of HIV and by restoring immunological function. In this study which was published in the June edition of a British medical journal - The Lancet - there were no significant side effects from the drug which is administered intravenously twice weekly. There was an immediate and striking clinical improvement in patients, but symptoms recurred when the drug was stopped. Two very important aspects have also been noted. First, it potentiates the efficacy of AZT so it may be used in combination and reduce the adverse side effects of that drug.

Secondly, it crosses the blood - brain barrier which most drugs do not. This is significant for treatment of central nervous system HIV infection (dementia, motor coordination, etc.) which may occur in as many as eighty percent (80%) of those infected with HIV over a long period of time.

Although Ampligen has not yet been approved for widespread usage by the FDA and is available at only a small number of AIDS Treatment Evaluation Units (ATEU's), it is our feeling that this type of medication may become the foundation of different types of combination therapy (eg with AZT) which maximize therapeutic effects and minimize toxic side effects.

HHS NEWS

HHS (U.S. Dept of Health and Human Services) Secretary, Otis R. Bowen, M.D., announced on Oct. 2, 1987 the award of $18.6 million in cooperative agreements for research on AIDS treatment, basic studies and outreach. Seventeen Clinical Studies Groups will be established in 10 states and the District of Columbia by the National Institute of Allergy and Infectious Diseases. The total projected funding for the groups is approximately $100 million for 1987 through 1992.

In announcing the awards, Dr. Bowen said, "Everyone is keenly aware that AIDS is an enormous and growing problem, demanding strenuous effort and creative solutions. This initiative is another example of how America's scientific talent is being mobilized to combat AIDS."

Through the clinical studies groups (CSG), NIAID can extend access to clinical trials of promising AIDS therapies to patients in a much wider geographic area than is now possible. The CSG clinical trials will be coordinated with the institute's existing 19 AIDS Treatment Evaluation Units, which were established in 1986 and early 1987.

"This program is generated by an exciting, innovative concept," NIAID Director Anthony S. Fauci, M.D., said. "We are attracting top-notch scientists into the field and we are facilitating partnerships between basic scientists and those doing clinical research on AIDS. We anticipate new and imaginative approaches to treatment and other problems posed by the complexities of the disease and the virus that causes it. In addition, through their outreach efforts the CSG's will perform research into methods of communicating health care information to other health care professionals and to the patient populations they serve.

"We are making a concerted effort to include in our clinical trials all groups at risk for AIDS, particularly hemophiliacs and children born to infected mothers. Through the CSG's we will develop leadership among a wide range of health care professionals who serve all the populations in which AIDS is spreading most rapidly; for example, blacks, Hispanics, intravenous drug users, bisexuals and homosexuals."

AIDS MINISTRY CONFERENCE

January 15, Friday:	9:00 am - 10:00 am	REGISTRATION
	10:00 am - 12:30 pm	OPENING BRUNCH 1) Keynote Speakers Rev. Elder Troy D. Perry Ms Ellen Ratner Rev. Renee McCoy Rev. Steve Pieters 2) Table Group Sharing
	1:00 pm - 2:30 pm	MEDICAL UPDATE Dr. Peter Mansell
	2:45 pm - 4:30 pm	WHAT PEOPLE WITH AIDS NEED FROM AIDS MINISTRY National Assoc. of PWA
	4:30 pm - 6:30 pm	BREAK
	6:30 pm - 8:00 pm	WORKSHOP SESSION I
January 16, Saturday	9:00 am - 12:00 pm	PASTORAL CARE
	12:00 pm - 2:00 pm	LUNCH TABLE GROUP SHARING
	2:00 pm - 3:30 pm	WORKSHOP SESSION II
	4:00 pm - 5:30 pm	WORKSHOP SESSION III
January 17, Sunday	10:00 am - 12:00 pm	AIDS AND PUBLIC POLICY Caitlin Ryan
	12:00 pm - 1:30 pm	LUNCH TABLE GROUP SHARING
	1:30 pm - 3:00 pm	WORKSHOP SESSION IV
	3:15 pm - 4:00 pm	CLOSING PRAYER SERVICE
	5:00 pm - 6:00 pm	CONFERENCE EVALUATION

The AIDS Ministry Conference will be held January 15-17, 1987 in Houston, Texas at the Westin Oaks Galleria. This Conference is Sponsored by: UFMCC Board of Elders and Samaritan College; Cosponsored by: National Lesbian & Gay Health Foundation, The Pride Institute, National Association of PWA, and National Coalition of Black Gay & Lesbians.

Cost for this Conference:

Before Dec. 31, 1987
Friday - Sunday $105.00
Saturday - Sun. $ 75.00

After Dec. 31, 1987
Friday - Sunday $130.00
Saturday - Sun. $ 95.00

For more information please contact: Samaritan College, 5930 Comey Avenue, Los Angeles, CA 90034; (213) 934-0122.